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Breast Cancer Treatment

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13. ABSTRACT (Maximum 200 Words) <p>When patients choose a treatment plan in a manner consistent with their values, preferences, and individual decision making style, they generally have better outcomes in part, because involvement also improves the quality of therapeutic decisions. Greater involvement may also optimize the decision-making process by which treatments are chosen thereby reducing untoward decision outcomes such as disappointment, regret, or depression.</p> <p>Using a multimedia CD-ROM format, Choices provides an innovative approach to personalized decision making by incorporating unique features that currently are not available in existing programs. The ultimate objective of Choices is to help patients make effective decisions under stressful and threatening circumstances. Specifically, Choices has the following unique features in contrast to existing programs: (1) the program is designed to be user-friendly and comfortable for women of all ages and education levels, (2) an assessment of the decision maker's personal decision style is used to set the structure of the program, (3) the program considers the cognitive demands of the decision making in this health care context, (4) it goes beyond eliciting personal values and preferences by providing solutions to common decision failures, and (5) provides an opportunity for pre-decision rehearsal of different options to avoid unexpected decision outcomes or negative emotional responses.</p>				
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INTRODUCTION

This project was initiated to develop an innovative decision support program for women with early stage breast cancer that captured available technology to provide individualized and empowering coaching to assist women in avoiding common decision errors. With this decision support system, we will now be able to address common shortfalls in unaided decision making by supplementing naturally-occurring processes with state of the science decision support. It is now possible to evaluate the physical, emotional, and psychological outcomes of women's decision making processes and determine the optimal strategies for aiding these decisions. The ultimate objective of the project is to enhance the quality of life of women facing breast cancer treatment by providing quality decision support that is effective, practical, and scientifically sound.

Choices was developed to address the stress, conflict, and uncertainty surrounding breast cancer treatment decisions that is so pervasive in our current health care delivery systems. Patient and provider relationships do not always provide for the level of support, information, and counsel that is required by women attempting to sort out the intricacies of decision options placed before them. Many patients are turning to books, videos, the Internet and various media technologies to help them through this difficult period. A shortfall of many of these sources is that they do not individualize the information to a particular woman, nor do they have the capacity to take into account, and tailor, the way the information is presented to optimize her reasoning capacity. Therefore, the specific aims of this project were to assist women and their families: (1) make active decisions about breast cancer treatment that takes into consideration their goals, values, and personal decision making style, (2) in making more informed decisions by providing readily accessible information, and (3) avoid common decision errors by rehearsing various outcome scenarios and making the necessary corrections to increase satisfaction with choice.

The scope and significance of this project rests on the potential it holds to enhance the quality of patient's decisions and potentially the outcomes of those decisions. Greater involvement, in partnership with tailored decision support, may also optimize the decision-making process by which treatments are chosen thereby reducing untoward decision outcomes such as disappointment, regret, or depression.

KEY RESEARCH ACCOMPLISHMENTS

Statement of Work

Our Statement of Work is provided in Figure 1 and describes the original plan to develop a prototype of an interactive decision support system for use by women diagnosed with early stage breast cancer. During Year 3 of the project, during prototype testing, the team enthusiastically identified additional components that could be developed that would enhance the quality and uniqueness of the program. At that point we requested an extension (please refer to this request of June 1999) to complete **additional components** that were not originally included in our schedule of activities.

Figure 1. Schedule of Activities for the Project Period From January 1, 1997 to June 30, 1999¹

	Year 1 1997				Year 2 1998				Year 3 1999	
Quarter	1	2	3	4	1	2	3	4	1	2
<u>PROTOTYPE DEVELOPMENT</u>										
Assemble advisory and technical panels										
Purchase equipment & supplies										
Develop systems plan for prototype										
Write and edit text for program modules										
Programming										
Laboratory testing of components										
Review of prototype by advisory panel(s)										
Preliminary field testing										
Prepare Interim and Final reports										
Prepare Papers for Presentation and Publication										

¹ In June 1999, we requested a one-year extension to complete additional components of the project, which will be addressed in further detail within this report.

With the approval of this extension, we modified the original prototype to include the following components: (1) decision style assessment, (2) value assessment, (3) decision support, (4) pre-decision rehearsal, and (5) analysis, feedback, and communication. In the midst of developing these modules, the team realized the potential for providing even more elaborated decision support and added components to the program. In addition, for the value assessment module, we developed two separate methods for eliciting values and have tested women's ease of use and preferences for the two methods. This item was beyond the original scope of the project but it addresses one of the major issues in decision science, which is to assess personal values without the burden of complex mathematical models, which are currently prevalent in the field. Patients, in particular, find these much too cumbersome to use and we have devoted a great deal of attention to the development of alternative models that are more user friendly and still yield important information. We have also developed individualized interventions based on the assessment of decision style that promises to provide more specific and tailored information than any other system currently available.

The program now uses the decision style information and creates individualized action plans that are composed of a number of additional components including: (1) My Plan (describes basic decision procedures; helps the decision maker understand the steps involved and ways in which decision support improves the process), (2) Selecting a Doctor and/or Treatment Facility, (3) Building a Support Team, (4) Gathering Information, (5) Communication Tools (the program is designed to help women easily communicate by preparing letters, lists of questions, reminders, "to do" lists, etc.), (6) Emotional and Physical Support, (7) Entailment and Reactive Costs (interventions to reduce potential post-decision regret by anticipating future setbacks and emotional reactions), (8) Reflection and Restoration, and (9) Declaring a Choice. The addition of these 9 components, as well as the development of two versions of the values assessment were beyond the scope of the initial project and have framed the Statement of Work for the period of work during the extension. Figure 2 contains the revised Statement of Work for the extension year from 1999 to 2000.

Figure 2. Revised Schedule of Activities from July 1, 1999 to August 31, 2000

	Quarter	4	1	2	3
Design format of 9 new components					
Plan programming flow chart					
Write text for new components					
Write new program language					
Edit and revise new material					
Refine prototype					
Prepare Interim and Final reports					
Prepare Papers & Presentations					

KEY RESEARCH ACCOMPLISHMENTS DURING EXTENSION

- Task 7 Months 24-26 Design format of 9 components Complete
- Task 8 Month 25 Plan programming flow chart Complete
- Task 9 Months 26-30 Write text for new components Complete
- Task 10 Months 26-36 Write new program language Complete
- Task 11 Months 33-36 Edit and revise new material Complete
- Task 12 Months 35-36 Refine final prototype Complete
- Task 13 Months 35-36 Prepare Papers In progress

REPORTABLE OUTCOMES

- Decision Support Prototype of originally-planned work is complete
- Additional tasks to be completed during the extension are complete.
- **Invited or Peer-reviewed Presentations (1997 – 2000)**
 - 1999 *Decision Control and Distress in Breast Cancer Treatment Choices*. Pan American Congress of Psychosocial and Behavioral Oncology. October 22, New York, NY.
 - 1999 *Addressing the Psychological Needs of Women Diagnosed with Breast Cancer: Providing Decision Support*. World Conference on Breast Cancer. July 30, Ottawa, Canada.
 - 1999 *Value-Based Decision Support for Early Stage Breast Cancer*. World Conference on Breast Cancer. July 27, Ottawa, Canada.
- **Invited or Peer-Reviewed Poster Presentations (1997 – 2000)**
 - 2000 *Choices: An Interactive Decision Support Program for Women With Breast Cancer*. Era of Hope: Department of Defense Breast Cancer Research Program Meeting. June 11, Atlanta, Georgia.
- **Papers in Progress**
 - “Decision Support Interventions for Breast Cancer Treatment”
 - “Elicitation of Breast Cancer Treatment Values”
 - “An Evaluation of *Choice*: A Decision Support Program for Women with Early Stage Breast Cancer.”
- **Funding Applied For Based on Work Supported by This Award**
 - 1999 Decision Support for Couples Facing Prostate Cancer Treatment. US Army Medical Research & Materiel Command. Not Funded
 - 1999 Choices: Breast Cancer Decision Support for African American Women. US Army Medical Research & Materiel Command. Not Funded
 - 2000 Tailoring Decision Support Interventions to the Needs of Low-income Minority Women. DOD Breast Cancer Research Program Concept Award. Not Funded.
 - 2000 Defining Decision Support for Women with Recurrent Breast Cancer. DOD Breast Cancer Research Program Concept Award. Alternate; awaiting funding decision.

CONCLUSIONS

Choices promises to address fill the gap regarding access to quality decision support that is critical to empowered and informed choice that is currently lacking in both our scientific understanding as well as our clinical care. This project represents an important first step in the effort to define optimal strategies for providing personalized decision support to empower women's self-determination and participation in cancer treatment decisions. The additional components provide unique procedural activities to decision processes that is characteristic of breast cancer decision making. Specifically, these modules have to do with (1) providing cognitive support during complex decision making activities, (2) providing cognitive and emotional rehearsal of competing decisions to allow the woman to experience potential decision satisfaction or regret before committing to a particular action, and (3) the provision of activities to bolster her emotional strength to better enable her to deal with this difficult treatment phase. The extension of time provided an opportunity to further develop a more complex prototype than was initially proposed. The resulting prototype will provide a more robust decision support product that has the capacity to individualize and tailor women's decision-making experiences. In the near future the team would like to explore the use of the World Wide Web to make the program available to a broad range of women from diverse ethnic and socioeconomic backgrounds. As outlined above, we have prepared a variety of proposals to address unmet decisional needs for couples facing prostate cancer, low income minority women, and women facing recurrent breast cancer. Although we have not yet been successful in obtaining additional funding, the resources provided by this first IDEA award has been extremely influential in addressing some of the burdensome and complex issues critical to providing sound decision support. Future ventures, and I'm sure there will be successful ones, will owe their success to this first and very important step.

PERSONNEL RECEIVING PAY FROM THE RESEARCH EFFORT

Penny F. Pierce PhD, RN	Principal Investigator
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J. Frank Yates PhD	Co-Investigator
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